Wisconsin Public Psychiatry Network Teleconference (WPPNT)

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HELPING PEOPLE WITH SCHIZOPHRENIA

- The Medical Model vs. a Rehabilitation Model
- Non-Pharmacological Approaches
- Applications to the Here & Now

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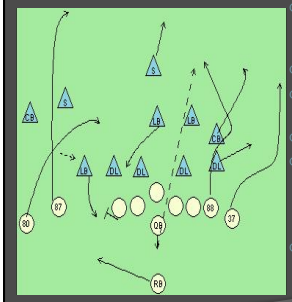
Today's Game Plan



- What Schizophrenia is and is not, and the spectrum of schizophrenia
- A little about Etiology
- The medical model: assumptions and implications
- A rehabilitation model
- Non-Pharmacological models:
  - Soteria
  - Open Dialogue
- Applications

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But 1st…How I got here….

- Grad School
- MHC…..then and now
- Robert Whitaker – Anatomy of an Epidemic
- Doctoral Students
  - Melinda Somogyi, Psy.D.
  - Amanda Dowling, M.A.
  - Emily Jirikowic, M.A.

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What Schizophrenia is….

- Schizophrenia is a Brain Disorder, which generally affects functions of:
  - ***Thinking***
  - ***Feeling***
  - ***Perceiving***
- Affects around 1% of the population, world wide
- Starts in teens to early 20s**
- As of today, it cannot be cured, but often can be effectively managed.
- The picture varies enormously in regard to:
  - Symptom expression
  - Severity
  - Outcomes (will discuss this more later)

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What Schizophrenia is *not*….

- "Split Personality"
- A response to trauma or stress
- "Burned out on drugs"
  - Is exacerbated by marijuana and cocaine
  - Exception: Methamphetamine seems to be quite capable of causing unremitting psychosis.
- A result of bad parenting

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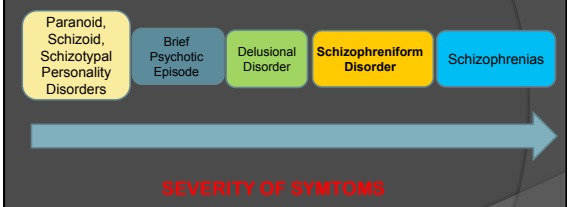
The Spectrum as a Continuum (per DSM-V)



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Clusters of Symptoms

- Feeling:
  - Blunted, flat, unemotional
  - OR, "affect" is "inappropriate" to the situation
  - Can be easily overwhelmed by emotions
- Thinking:
  - Concrete: The "chickens" story.
  - Loose associations: make connections to irrelevant aspects. Example with "Proverbs"
  - Tangential: Can't stay on topic
  - "Neologisms" ("brush on plaque")
  - Slowed, impaired information processing
- Perceiving:
  - Hallucinations
  - Delusions
- NOTE: Everyone does not have all of the symptoms.

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Information Processing

- Frontal Lobe Activation
- Attention/Concentration
- Difficulty screening out irrelevant stimuli
- Stimulus Overload
  - Equipotentiality of all stimuli
  - Emotions as stimuli
  - Expressed Emotion

Schizophrenia has a Profound Effect

- The condition has a profound effect on a person's psychosocial world:
  - Consider what is happening in life when it begins
  - Effects on education, employment and SES
  - Social Stigma
- Persons with a diagnosis of schizophrenia can expect a life expectancy of 15 years less than the non-ill population.
- Lifetime Risk of suicide = about 5.6%

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Some Videos to Watch

- John Nash
  - https://www.youtube.com/watch?v=SizS1nOOeJg&list=PL83EB4759EDD815F1
  - http://www.youtube.com/watch?v=0UOOkS6vJ1s&list=PLF9AFFCD95C4CD17D
- A Beautiful Mind
- The Soloist (but, the book is far better)

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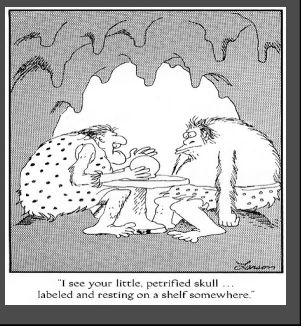
The Brain and Biology

Structural Findings
Neurotransmitters
Genetics
Environmental Factors


"I see your little, petrified skull . . . labeled and resting on a shelf somewhere."

Biological Evidence

Genetic

- **1% incidence in general population**
- **48% if identical twin has schizophrenia**
- **46% if both parents have schizophrenia**
- **16% if one parent has schizophrenia**
- **9% if one sibling has schizophrenia**
- **6% if a half sibling has schizophrenia**
- **2% if an uncle or aunt has schizophrenia**

Structural Brain Imaging Findings

- Progressive loss of brain tissue
- Begins in adolescence, and continues progressively
- Majority of loss is in the frontal and temporal areas
- Larger amounts of loss associated with:
  - Poor outcome
  - Negative Symptoms
- Does not relate to the history of medication dosing
- Similar pattern seen in in healthy full siblings

More Biological Evidence

Functional Imaging Studies

- Routinely find differences in patterns of cortical activation
  - Using glucose metabolism
  - Measures of blood flow
- Failure of frontal lobes to "activate" with onset of a task.
- Andreasen (2008) found reduced blood flow to anterior cingulate gyrus and posterior hippocampus on a social reasoning task.

The Effect of Antipsychotic Medications

- Produces a reduction of positive symptoms in at least 80%
- Potency related to the effectiveness in blocking specific dopamine receptors
- New drug being tested targets *glutamate*

However…none of these alone is diagnostic

Traditional Picture of Course

- RELAPSE:
- 80% of treated patients relapse at least once within 5 years of the initial episode.

- 12.2 % = One episode only, no further impairment
- 14.6 % = Several episodes, with minimal impairment
- 17.1 % = Some continuing impairment after the 1st episode, with some additional episodes.
- 33 % = Repeated episodes with increasing impairment & negative symptoms.
- 11 % = Symptoms and impairment persist after the 1st episode without significant remission.

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The Medical Model of Treatment: Assumptions

- Schizophrenia is a physical sickness, a physical state which is improper, and needs to be medically corrected.
- If this underlying medical/physical condition can be corrected, the person will be "well".
- Social factors are seen as peripheral

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The Standard of Care in the US

- Follows from this Medical or Disease Model
- The primary focus of intervention is the use of antipsychotic medication to correct the impaired physical state
- Therefore, the key to a good outcome is **<u>medication compliance</u>**
- Social support, therapy, education, vocational experience are usually secondary.
- The take away message is that you have a chronic *illness*.

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Implications of the "take away message"

- I'm sick, and I'll have "this" for the rest of my life.
- I won't be able to go to school, pursue a career, etc.
- My goals will be out of my reach.

WHO WOULD WANT TO ACCEPT THIS MESSAGE?

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What happens when a young person is diagnosed with schizophrenia?

- Family/caregivers frightened
- Seek medical care: Labeled as "sick"
- Lowered expectations
- Subjective experience:
  - Their experience is a function of this "sickness"
  - Isn't real, "…all in your head."
- Medical Care
- Social alienation begins

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Implications for a person experiencing schizophrenia

- Invalidation of their *experience*, which is seen as *just a symptom of a sickness*
- Withdrawal and social isolation
- Development of an unhelpful personal understanding/interpretation of their experience.
- "Squashed goals"
- Adversarial relationships with:
  - Providers
  - Family

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Why Not Take Meds?

- 75% of patients discontinue their medication within 18 months. Why??
- Unwilling to accept that they have the disorder
- Symptoms are seen as positive, and so do not want them treated:
  - Talking to God is a good thing
  - The voices are funny, are my friends, they keep me company
- Expectation meds won't work:
  - "How can a pill stop the devil?"
  - "How can pills do anything about the corporate conspiracy that's ruining my life?"
  - 2nd hand experience with relatives, etc.
- Negative Expectations:
  - The "drooling zombie" image
  - "I don't want to be controlled by drugs"
  - "I don't want to be dependent on drugs"

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More reasons patients don't take meds…

- Perception that the medication does not help
  - They do not see the changes others see
  - They may not see that the symptoms were a problem, so their absence is not a benefit.
- A realistic cost-benefit appraisal, including experience and concern about side effects.

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What we *DON'T* hear about…

- In fact, many people get better with little or no medication use.
  - Vermont Studies
  - Rappaport
- WHO has reported outcomes for people with schizophrenia in non-industrialized countries are better than those in the US and the UK.
- "Clinician's Illusion"

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Has Modern Treatment Helped?

Global recovery rates, based on a meta-analysis of 320 studies across a span of 100 years. From Mueser & Jeste, 2011 (p. 100)

1895-1955	1956-1985	1986-1992
35%	49%	36%

Vermont Longitudinal Study (Harding et al., 1987)

- 269 persons Dx with schizophrenia in mid 1950's (using DSM-I)
  - Chronically ill for an average of 16 years, disabled 10 years
  - Had received phenothiazines for about 2 ½ years
  - These people were *retrospectively re-diagnosed* with DSM-III criteria using hospital records:
    - **118 retained as meeting DSM-III criteria.**
  - Of these, **82** could be located and were interviewed 20-25 years after the index hospitalization.

Vermont Longitudinal Study: Findings at Follow-Up

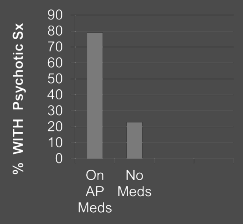
- **68% had no signs of schizophrenia**
- **45% showed no psychiatric symptoms at all**
- 23% shifted to a probable affective or organic disorder
- **Medication Use:**
  - 84% were prescribed psych medications
  - 25% reliably took the medications
  - 25% self-medicated only when having symptoms
  - ***50% were functionally medication free***
    - 34% did not take the prescribed medications
    - 16% not *prescribed* any medication

Harrow & Jobe, 2007

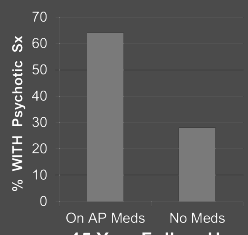
Chicago Follow-Up study

- 64 patients Dx schizophrenia on DSM-III from Illinois public and state hospitals, and 81 non-schizophrenic patients.
- FU at average of 2, 4.5, 7.5, 10 and 15 years.
  - 76% interviewed at all 5 FU points
  - Another 16% at 4 of the 5 points
  - Looked at:
    - Med Use
    - Symptoms
    - Employment and social adjustment

Psychotic Sx at 10 & 15 Year Follow Up (Harrow & Jobe, 2007)



10 Year Follow-Up



15 Year Follow-Up

Long Term Outcomes (Torrey, 106)

10 Years After 1st Professional Contact

25%	25%	25%	15%	10%
Completely recovered	Much improved, relatively independent	Improved, but requires extensive support network	Hospitalized, unimproved	Deceased

30 Years After 1st Professional Contact

25%	35%	15%	10%	15%
Completely recovered	Much improved, relatively independent	Improved, but requires extensive support network	Hospitalized, unimproved	Deceased

Some conclusions

- The course of schizophrenia is not necessarily as dismal as it is portrayed.
  - Even by Torey's standards, 60% are ultimately "completely recovered" or "relatively independent."
  - Vermont Study suggests almost 70%
- Many succeed with little or no medication, even without specialized help

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An Alternative: A "Rehabilitation Model"

- Analogy to a stroke
  - It is a physical condition that produces mental (and sometimes physical) changes
    - Speech
    - Memory
    - Motor & Sensory function
  - Treatment Strategy?

Things that are DONE	Things that are NOT DONE
•Provide hope	•Invalidate experience
•Practice and develop lost skills	•Sedate with medication
•Compensatory Strategies	•Isolate from social network
•Engage family	•Wait to treat until the person is forced to engage.
•Begin treatment immediately	

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Alternative Treatments
Let's think OUTSIDE the box

"Never, never, think outside the box!"

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Non-Pharmacological Approaches to Treatment

Soteria House
Open Dialogue

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Soteria House & Emanon House

- Locations:
  - San Francisco, 1971-1976
  - Emanon House 1976-1982
  - Soteria House-Alaska (2008)
  - Soteria, Berne, Switzerland
- Purpose: To provide a choice/alternative to the standard treatment which relied on antipsychotic medication.

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Description of Soteria & Emanon House

- Community setting in the San Francisco Bay area
- Homelike setting for 6-8 individuals. Quiet, supportive, protective, tolerant social environment.
- 24-hour day application of interpersonal phenomenologic interventions performed by nonprofessional staff
- No neuroleptics for at least 6 weeks.
- Nonintrusive, noncontrolling, empathetic
- Being with the person
- Staff to develop a shared experience with the patient.
- Goal is to share, understand, and communicate these disorganized states of psychosis and their relationship with the life events which precipitated these mental states.

Soteria Principles

- No medication without agreement
- Used non-medical staff, without preconceptions about the treatment of psychosis.
- Key components
  - Acceptance , understanding and validation of the experience.
  - Soteria as a mutually supporting *community* or social network. Members stay in touch & involved after discharge
  - Self-Determination

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The NIMH Funded Study

- Young, unmarried, 1st or 2nd episode.
- Care at Soteria House compared to "treatment as usual": hospitalization, medication, outpatient
- Individuals presenting for admission at the local hospital who met criteria were randomly assigned to either Soteria or the CMHS.

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Outcomes

6 Weeks

Both groups showed significant improvement in symptoms

But, those at Soteria received little or no meds.

Average LOS about 6 weeks at Soteria compared 30 days at CMHS

2 Years: Soteria patients:

- Similar levels of symptoms
- Had a lower frequency of rehospitalization. (Even though only 10% of the Soteria patients received any medication.)
- More often living independently
- Higher levels of occupational functioning

Conclusions from Soteria

- People treated psychosocially had no worse symptoms at 6 weeks and 2 year follow-up than those treated with meds.
- However:
  - They FUNCTIONED better in the community.
  - And so, had fewer relapses
  - Typical LOS was much longer

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Open Dialogue

- Developed in Finland, beginning in 1980s.
- In response to a national mandate to develop alternatives to hospitalization.
- Influenced by principles of systems and communications theories (such as family therapy).
- Replicated in Sweden, Latvia, Lithuania, Norway

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Key Components

- Early Identification, and rapid response (within 24 hours)
- Delivery of care primarily in the community, typically the person's home
- All staff meet with client, family members, relevant social network (friends, neighbors, teachers, employers)
- No separate meetings for clinicians
- Medication use is NOT "Plan A"

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Treatment Team –Family Meetings

- Multidisciplinary, all trained in family therapy.
- All discussions and decisions are made within these meetings
- Eliminates disease model:
  - No hierarchy – no one person is viewed as being more important.
  - Subject not viewed as sick, but as someone to be understood.
- Generates dialogue that leads to a common understanding, which becomes the basis of care.
- The purpose is not to eradicate symptoms but, rather, to take a understand and find meaning to them.

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Goals and Principles

- Living through the crisis together
- As clients are supported and gain a stronger voice, this leads to empowerment and meaningful participation in decision making and goals regarding their lives.
- Recovery from psychosis occurs between people, resulting in much less reliance on meds and hospitalization

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Open Dialogue: Outcomes

Seikkula, et al., 2006

- Five-year Study:
- 83% of patients returned to jobs or school or were looking for a job
- 77% patient did not exhibit residual symptoms
- This surpassed outcomes for those who received conventional treatment (hospitalization, medication, and outpatient follow-up).
- Regarding the catchment area:
  - 50% decrease in need for inpatient treatment
  - 40-60% decrease in patients with psychotic symptoms
- Claim: There is no longer any chronic mental illness in the catchment area.

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Applications of Open Dialogue in the US

- Burlington, Vermont (scheduled to open this year)
- Collaborative Pathways, Framingham, MA.: Open Dialogue Pilot Project.
- Institute of Dialogic Practice: Training institute for Open Dialogue
- Parachute, NYC: Pilot project to provide in-home care as an alternative to hospitalization in New York City.

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Soteria & Open Dialogue: Common Elements

- Conceptualization of schizophrenia as a valid experience to be shared and understood, rather than an illness to be fixed.
- Maintain or develop the person's engagement in their social network.
- Empowerment
- Emphasis on adaptive functioning
- Early Identification
- Subordination of psychotropic medication in the program of care

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Take Away Concepts We Can Apply Now

- It's all about the relationship
  - Listening
  - Understanding
- Finding some adaptive meaning to the experience
  - Most delusions DO mean something
- Purpose, Meaning, and interpersonal connection are key factors (*A Beautiful Mind)*
- It's really about *functioning* NOT "symptoms"

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Examples/Illustrations

- Social isolation due to stigma and fear lead to maladaptive interpretations of symptoms.
- Working with delusions:
  - Grandiose:
    - Compensatory: Richard, Michael (& father), Phil
  - Persecutory: Grains of truth
  - Religious: Father was a evangelical minister
  - Go with the delusion: "Brush on plaque"

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Role Models: Patricia Deegan, Ph.D.

- Who she is.
  - YouTube video: http://www.youtube.com/watch?v=DVIhfuKDjYE&feature=BFa&list=PL83EB4759EDD815F1
  - She also has a YouTube channel devoted to Recovery.

http://www.youtube.com/user/patdeegan?feature=results_main

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